

## Understanding oral health challenges for children and young people with autistic spectrum conditions: views of families and the dental team

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# **UNDERSTANDING ORAL HEALTH CHALLENGES FOR CHILDREN AND YOUNG PEOPLE WITH AUTISTIC SPECTRUM CONDITIONS: VIEWS OF FAMILIES AND THE DENTAL TEAM.**

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**KEY WORDS:** Autism, autistic spectrum conditions, dental experience, dental team, dental anxiety, sensory difficulties

## **ABSTRACT**

Understanding oral health challenges for children and young people with autistic spectrum conditions: views of families and the dental team.

## **INTRODUCTION**

Anxiety regarding dental procedures and fear regarding dental re-attendance when families have experienced problems relating to difficult behaviour at a previous visit, can result in unmet dental treatment needs for patients with autism.

## **AIM**

The aim of this project was to involve key stakeholders meaningfully to gain understanding of the issues and challenges facing children and young people with Autism Spectrum Conditions (ASC) when they attend for dental visits.

## **Methodology**

Qualitative data regarding dental experiences was gathered from children diagnosed with ASC, parents of children with ASC and dental service providers. Children were engaged to participate, where possible, in interviews with their parents present. Individual interviews were conducted with parents of children from across the autism spectrum (with and without learning difficulties) and across ages from 5 to 14 years. Information from primary care dental providers was gathered through participation in a focus group discussion.

## **DISCUSSION**

Sensory difficulties, dentist expectations and attitudes, and lack of pre-visit preparation for dental visits were highlighted as important factors influencing dental experiences for patients with ASC and their families.

## **CONCLUSION**

Pre-appointment preparation and education regarding ASC were identified as areas where positive action could be taken to improve dental experience. Sensory reactivity was identified as a common and significant obstacle to optimal oral care requiring further research.

## **AIM**

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## **INTRODUCTION**

Autism spectrum conditions (ASC) can involve impairment in social interaction and communication, combined with restricted interests and rigid and repetitive behaviours (NICE, 2011). About 1 in 68 children has been identified with ASC (Christensen et al., 2016) which is reported to occur in all racial, ethnic, and socioeconomic groups.

Children with ASC can have problems complying with preventive dental care regimes at home as well as co-operating with dental requests in the surgery. There is no "one size fits all" approach to dental and oral care for children diagnosed with ASC as the condition encompasses a wide spectrum of capabilities and behaviours (Lewis et al., 2015). Patients with ASC have not been identified as having higher caries prevalence (Blomqvist et al., 2015). However, the gingival health of children with autistic spectrum conditions (ASC) has consistently been found to be significantly poorer than typically developing children (Luppanapornlarp et al., 2010; Bartolomé-Villar et al., 2016). Considerable challenges for dental patients with ASC stem from problems coping with sensory input in the dental environment (Charles, 2010; Stein et al., 2011). Smell and taste reactivity have been noted in children with ASC (Schoen et al., 2009). While atypical sensory symptoms are not unique to ASC, over 65% of children with ASC have been found to have sensory reactivity problems (Tavassoli et al., 2016). The most recent Diagnostic and Statistical Manual (DSM-5) criteria

for ASC includes over- and under-reactivity to sensory input as well as sensory craving (American Psychiatric Association, 2013). Parental and professional efforts to improve oral health are frequently hampered due to oral defensive behaviour which can also affect mealtime behaviour and diet in children with ASC (Provost et al., 2010).

Although caries rates may not be higher, anxiety regarding dental procedures as well as fear regarding dental re-attendance, can result in unmet treatment needs and eventual costly treatment modalities such as dental general anaesthesia even for minor procedures (Lai et al., 2012; Isong et al., 2014).

Research has demonstrated that children with ASC have higher anxiety levels compared to typically developing children (van Steensel and Heeman, 2017). Attending dental appointments to assess oral needs can be extremely stressful and demanding for a child with ASC and their family with approximately 50 – 72% of children being reported as anxious and uncooperative at the clinic (Marshall et al., 2007; Loo et al., 2008; Brickhouse et al., 2009).

Unlike a medical practice where attendance is usually motivated by need, regular attendance at a primary care dentist is recommended. Oral health review for many children and young people with ASC can be recommended as frequently as 3 monthly due to high oral risk status associated with behavioural, dietary or other special needs. Dental examinations, radiographs and preventive procedures are the most regular invasive interventions any child experiences. Dental visits can be even more challenging for those with ASC.

This project sought to involve all key stakeholders to gain understanding of oral health challenges associated with delivering and receiving oral healthcare, with a view to aiding improved dental experience and re-attendance in the primary care dental setting for patients with ASC.

## **MATERIALS AND METHODS**

Service users, their families and dental professionals were consulted regarding dental experiences of children with ASC, and changes which might be beneficial to address issues highlighted.

The project was given ethical clearance by the University of Sussex Ethics Review Committee. Data was anonymised. Children were only included with their parents present. All participants had the right to withdraw at any stage.

The study was designed to gather qualitative data regarding dental experiences from children diagnosed with ASC, parents of children with ASC and dental service providers. Child and parent participants were recruited via an invitation letter to schools providing specialist educational provision for children with ASC. Dental provider participants were recruited from invitations delivered at local dental committee (LDC) meetings. A focus group was conducted with general dental service staff (GDS) (n=8). Individual interviews were conducted with parents of children from across the autism spectrum (n=7) (with and without learning difficulties) and across ages from 5 to 14 years. Three children were engaged to participate in interviews with their parents present. Pictures and dental objects were used to support the children's communication in the interviews which were mainly carried out in family homes.

The data from the interviews and the focus group were transcribed verbatim in order to capture all possible data at the initial stage and the transcripts were read in detail several times in order to familiarise the researchers with the scope of the data. The transcripts were then analysed using Nvivo qualitative data analysis software as a thematic analysis tool and

initial codes were generated (Braun & Clarke, 2006). The codes were then linked to broader emerging themes pertinent to the aims of the project and the frequency and prevalence of their iteration. The themes included: sensory difficulties, dentist expectations, dentist attitudes and preparation for dental visits. These themes were explored for strategies to manage change which could improve dental experience for children diagnosed with ASC.

## RESULTS

Focus group and interviewed participants are outlined in Table 1.

**Table. 1** Participants Details

Interview participants	Focus Group participants
Parent A and Child A	Dentist 1
Parent B and child B	Dentist 2
Parent C and Child C	Dentist 3
Parent D	Dentist 4
Parent E	Dentist 5
Parent F	Dental Nurse1
Parent G	Dental Nurse 2
	Dental Nurse 3

### *Sensory difficulties*

Atypical sensory symptoms were highlighted as particularly challenging within the dental environment. Most comments from parents and children related to oral intrusions into the mouth with various tastes and textures feeling unpleasant or unwelcome. Child B also said that he was afraid of the dentist “hitting his gums with the mirror”. Several parents commented specifically on dental lighting as a problem. Child B was very clear that the overhead lights were too harsh for him. One dental nurse reported an incident with a child in

the communal doctor / dentist waiting room who came running in and went behind the desk and switched all the lights off ..” *he was about 7 years old and he just couldn't cope with them so he just switched them all off* (Dental Nurse 2).

Some parents talked about auditory processing issues and how specific sounds can cause physical pain for children with ASC. Noise levels from dental drills and tools, as well as background clinic noise are extremely distressing for these children. Parents described encouraging their children to use ear defenders in the dental environment.

GDS dentists suggested a training need regarding preparation for the kind of sensory reaction which is often displayed by children with ASC. Although interviewed on separate occasions, parents also commented on the likely benefit of education regarding the unique individual needs of patients with ASC, for clinicians. Some parents believed that difficulties associated with ASC which may include a restrictive diet were not recognised by dental staff. They were keen for dentists to understand that some restricted diets were related to sensory reactivity issues rather than poor family diet and habits. Parents commented that “*oral care messages are often patronising*”, that parents “*know the messages and have other children with good teeth*”. Parents felt that dentists may not appreciate that a child with ASC may have a very restrictive, “faddy” diet which because of ritualistic type behaviour is very difficult to change. Parent E said dentists did not individualise oral health advice ... “*it was almost like they were talking about the average child and you think the reason I’m here [in this case at the special care dentist] is because this isn’t the average child*”.

One parent believed that the whole process of being a dental patient is just too demanding ‘*I think it’s the whole thing, and I think for someone to ask her to sit in a chair, put her head back and open her mouth, you know, it’s hard enough getting her dressed*’ (Parent E).



### ***Dentist expectations and attitudes***

There were more accounts of negative than positive dental experiences from parents and children. Child B described a visit where the dentist had physically intervened to open his mouth, *‘I didn’t open my mouth because I didn’t trust him so he, um, pulled it open and I didn’t like it’*.

Parents considered a personalised and less time restricted approach most important. One parent suggested *“If you can give anything (to children with ASC) – give TIME....if I start shoving my child into a room she thinks “what is this about”. She needs time to process the demand – don’t keep repeating...just say once but allow time to process. My child needs to go back to beginning to start thinking again each time you give a new command. Fewer words are needed – just time”*.

Dentists described their commissioned target based NHS units of dental activity. There was general agreement that *“getting things done quickly and efficiently is important to reach target”*. Dentists described how efforts to meet targets can restrict the likelihood of longer or more frequent “familiarisation” appointments being booked. Dentists within the focus group expressed a wish to build rapport and keep families seen together within the practice where possible. This relationship was seen as an investment for all concerned, *‘I think it’s more rewarding if you can build up a rapport and get somewhere ‘cos it just feels like a failure sometimes to refer a patient’* for behaviour issues (Dentist 2). One GDS dentist talked about the significance of return visits and how the early years had been difficult with some autistic children he sees but now this investment of time and patience had paid off,...*“it’s been very difficult when they’ve been four, five, six, or seven, and trying to manage them, but you know, they’ve kept coming back, they’ve been OK to come back and then they suddenly change and they become a bit more accepting of the treatment and they are still coming in and by the*

*time they're ten, eleven, twelve, they love it!"* (Dentist 5). Dentists were unhappy about referring children out of their practices, but they believed that salaried services possibly have more time to carry out multiple introduction visits and are more specialised in managing atypical behaviour.

Some salaried dental services are called special care dental services. Interestingly this terminology was confusing for parents who often referred to the special care dental services as "*the specialist dentist*". There were higher expectations of what that dentist could do for the child or could do to support the parent. Parent A had had some negative experiences at a local family dentist. Her expectations were high that the "*specialist dentist*" would know what they were doing but '*actually it was just like going to the normal dentist.*'

### ***Preparation for dental visits***

Several parents called for pre-visit familiarisation and repeatable structure to clinic visits. One parents advised that for her child with ASC routine was very important..." *with routine suddenly things will click...it is a big problem if she feels out of control and doesn't know what's coming next and negative experience is such a setback*". Some children build up positive relationships with particular members of staff. Staff change can result in significant deterioration in behaviour. However parents and dentists agreed that staff changes are inevitable.

Parents often helped to prepare their children using stories, role play or social stories. None of the parents or dental staff was aware of dental pre-visit questionnaires for children with autistic spectrum condition (ASC) which can help preparation for the dental visit (NAS, 2017; Nelson et al., 2015; British Society of Paediatric Dentistry, 2017). Dentists suggested that they would be keen to utilise information gathered prior to the visit regarding communication, preference, likes and dislikes. Dentist also advised that they felt parents

assumed that the dental clinician or practice had prior knowledge of a child's diagnosis. They were critical that often the diagnosis was not disclosed until the dentist encountered a problem with behaviour or compliance. Parents suggested that the reason for lack of disclosure was because they were not asked for the information on most medical history forms. Parents believe they were only being asked about medical conditions such as asthma, epilepsy etc. and that ASC was not a similar "medical" diagnosis.

Parents held very strong views on waiting and waiting rooms. Parents interviewed explained that with a child with ASC, they always prefer the first appointment. They advised that their children did not understand waiting and they "*needed to get straight in*". Even with a first appointment parents revealed personal feelings of frustration when they could hear a dentist and nurse chatting or laughing during preparation for a clinic to commence. Parents of ASC children, they revealed become "*masters of timing*".

## **Table 2**

### **Recommendations for improving dental experience for children with ASC**

Understand the ASC is a common condition – approximately 1% of children
Raise awareness by asking about any diagnosis of ASC when taking a medical history
Be aware that greater levels of sensory sensitivities may contribute to poor oral health
Always take parents' concerns and the child's or young person's concerns seriously
Behaviour techniques used for neurotypical children may be ineffective for children with ASC
Involve the family prior to and during visits to develop strategies to help reduce dental anxiety

## **DISCUSSION**

This project draws on the views of self-selected parents, children and dentists. Other studies have used qualitative data and thematic analysis to explore oral care experience of parents of children with ASC (Brown et al, 2014; Lewis et al, 2015; Thomas et al, 2018), but none to our knowledge have investigated the attitude of primary care general dental practice teams in the UK towards children and young people with ASC, or listened directly to the voices of children with ASC regarding their dental experience.

Although this study had a small sample size, it was designed to commence an engagement process with all key stakeholder to help gain better understanding of the problems associated with accessing, re-attendance and delivering oral health care for children and young people with ASC. The three children who participated were capable of articulating their views. Participation of children and young people with ASC was sought to meaningfully contribute and help improve dental experience for other children and young people with ASC who might not be able to engage because of additional disability and/or lack of verbal or other communication skills. Parents and dentists had positive ideas about how dental visits for autistic children could be made more successful than their current experiences suggest. In particular there were ideas about planning and preparing for visits to the dentist. Existing resources should be considered for use by dental professionals for appointment preparation (NAS, 2017; Nelson et al., 2015; British Society of Paediatric Dentistry, 2017). Further larger scale research utilising similar study design to engage families by listening to their questions and ideas is likely to help provide targeted training for the dental team to better understand and feel more confident about providing oral care for patients with ASC.

A key barrier to emerge from dental practitioners was diagnosis disclosure. This could be remedied by including a direct question within the medical history form. Parents were acutely aware of the impact of a bad dental experience at the dentist which can set back co-

operation and even attendance for future visits dramatically. The dental provider group were keen to work with parents to make dental visits more successful and less stressful for children.

An area highlighted as requiring further research was dealing effectively with issues relating to atypical sensory processing and oral defensive behaviour. Collaborative work nationally and internationally is required to understand sensory over-responsivity in the dental setting and measure success, utilising increased study size, of environmental adaptations which could benefit children and young people with ASC.

## **CONCLUSION**

This project identified emerging themes and relevant information to help support autistic children overcome barriers in attending the dentist including pre-appointment preparation and education regarding ASC for dental providers. Sensory reactivity was identified as a common and significant obstacle to optimal oral care requiring further research.

## **Declaration of interests**

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